DOCUMENT RESUME

ED 408 521 CG 027 765

AUTHOR Gold, Skye R.; Derevenco, Maria R.
TITLE A Psychoanalytic Exploration of HIV Status Disclosure to Children.
PUB DATE 13 Aug 96
NOTE 15p.; Paper presented at the Annual Meeting of the American Psychological Association (104th, Toronto, Ontario, Canada, August 9-13, 1996).
PUB TYPE Information Analyses (070) -- Speeches/Meeting Papers (150)
EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Acquired Immune Deficiency Syndrome; Children; *Childrens Rights; Confidentiality; *Disclosure; Elementary Education; Fear; Guilt; Parent Attitudes; Parent Responsibility; Privacy; Psychological Characteristics; Psychological Patterns; Student Rights

ABSTRACT

As the AIDS epidemic grows, society is faced by a growing number of children who are born HIV infected. Unfortunately, little systematic research has been conducted which addresses the psychological and social ramifications of HIV status disclosure to children. While most parents prefer not to inform the child of the illness, most clinicians favor disclosure. Some of the issues and questions favoring disclosure are explored in this paper. Some of the questions addressed include "At what age is the child able to comprehend the facts of seropositive status?" "How will disclosure affect the child psychologically?" and "How will disclosure affect the child's life and relationships in social settings?" Research shows that parents influence the psychological implications of disclosure; some of the barriers to disclosure include guilt and shame, the fear of social consequences, and the fear of death. Likewise, children's responses to disclosure are important to understand and such information must be viewed as a process. Some of the questions confronting researchers and parents when deciding whether or not to inform a child of his or her illness include, "What are the roles of this debate?" and "Is disclosure beneficial or not?" Contains 28 references. (RJM)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 408 521

A Psychoanalytic Exploration of HIV Status Disclosure to Children

Skye R. Gold, M.A., & Maria R. Derevenco, Psy.D.

HIV/AIDS Center Programs

St. Luke's/Roosevelt Hospital Center, NYC

Unpublished material. Please do not distribute or photocopy without authors' permission.

Paper presented at the 104th Annual Convention of the American Psychological Associatio, Toronto, Canada, August 13, 1996

BEST COPY AVAILABLE

c1996

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

S. Gold

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)"

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☐ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

CG027765

Introduction

As the AIDS epidemic grows, we are confronted by increasing numbers of children born HIV infected; in addition, now more of these children live past infancy. Almost seven thousand cases of AIDS were reported in infants and children under thirteen years of age through December 1995 (Centers for Disease Control and Prevention, 1995). In New York City alone, 1,645 pediatric AIDS cases were reported up to March 1996; of these 1,004 children are known to have died (New York City AIDS Surveillance Report, 1996). Most HIV infected children are born to poor, single women, who acquire the virus through heterosexual contact with intravenous drug-using partners, or through their own drug use (Wiener, Rickert, Theut, Steinberg, & Pizzo, 1995). Families with an HIV infected member experience severe medical, social, psychological, and relationship stressors related as much to poverty and substance use as to the illness (Tiblier, Walker & Rolland, 1989; Mellins & Ehrhardt, 1994).

HIV infection in children confronts parents and caregivers with the daunting questions of HIV status disclosure. At what age is the child able to comprehend the facts of seropositive status? How will disclosure affect the child psychologically? How will the disclosure of this information affect the child's life and relationships in social settings such as family school or neighborhood? And, will the child expose family secrets by openly discussing HIV infection with teachers, friends, and other community members? These are among the myriad questions that arise in connection with HIV status disclosure to children.

A basic question is that of the usefulness or advisability of disclosure. Research on children with cancer suggest that withholding information about diagnosis does not protect the child from experiencing the distress of the disease, and that disclosure of

diagnosis actually reduces anxiety, improves family functioning, and helps in long-term psychosocial adjustment (Claffin & Barbarin, 1991). AIDS, like cancer, forces the child to deal with death

precociously (Trad, Kentrose, Solomon, & Greenblat, 1994). Greenham and Lohmann (1982) support the notion that children as young as three years of age understand death. Overall, children within a broad age range can discuss their impending deaths if they have had the opportunity to freely discuss dying in the early stages of the illness (Schowalter, 1983). In our experience of running a group for children who know their diagnosis, they are able to discuss their understanding of death, of the death of parents and siblings, as well as their own wishes for their own funerals and burials. In fact, the truth is generally less threatening to a child than the fear of the unknown (Pollock & Boland, 1990), as children often invent their own complicated, incorrect, and self punitive explanations (Pollock & Thompson, 1995). Furthermore, as pointed out by Zelig (1974), children lose confidence and trust in parents and physicians when they sense that the adults are concealing the truth. Given the possible benefits of disclosure and the conceivable harm in non-disclosure, the clinical question becomes not whether, or when the child should be told, but rather how one should speak with children about their disease (Lipson, 1993)?

Unfortunately, little systematic research has been conducted in relation to the psychological and social ramifications of HIV status disclosure to children. While broader discussion of the ethics of disclosure to children is beyond the scope of this paper, we take a pro-disclosure position. In keeping with the ethical principle of autonomy, we believe children have the right to know their diagnosis and prognosis, and, as the disease progresses, to prepare for death. Children also should have the right to accept or refuse highly unpleasant or invasive treatments. For example, Evans (1995) argues for greater involvement of children in decision making related to the use of life sustaining treatment. Another study by Graham, Wass, Eyberg, and Chu (1989) supports the view that open communication between dying children and the adults who care for them benefits the children. Clement, Ziegler, & Cruickshank, 1996, noted the benefits of disclosure to include increased confidence, decreased fear and anxiety in children after disclosure, as well as heightened support for the family. Furthermore, disclosure of family secrets may prompt family change, often the main goal of therapy (Edmonds, 1988). Based on our work with a pediatric population in a family-centered HIV/AIDS primary care clinic, we will examine some of the psychological issues related to disclosure, hoping to highlight research and clinical needs and implications. In our experience,

clinicians tend to be in favor of disclosure, while parents are generally at best conflicted, and most times reluctant to disclose a child's HIV positive status. In our clinic only eight out of forty nine children (16.5%) know they are infected. Significantly, six of the children live in kinship foster arrangements and only two live with a biological parent. Their ages range from 8-13, and all of the children have experienced deaths of significant others.

Meanings and Psychological Implications of Disclosure

We will first examine the psychological meaning of disclosure as a way of understanding parent's responses. AIDS is unlike cancer and other fatal diseases in children in that currently the vast majority of pediatric HIV infections occur in utero or perinatally. Unlike other vertically transmitted diseases, such as Tay-Sachs or Sickel cell, also passed on to children unknowingly and unwittingly, HIV infection of the child is inextricably related to maternal behaviors stigmatized by society. As Lipson (1993) showed, children themselves would likely disapprove of such high risk conduct.

It is likely that one of the child's first reactions upon being told of an HIV diagnosis would be to ask how she/he was infected, thus exposing the mother's guilt regarding her destructiveness toward the child. Winnicott (1963) has discussed the coexistence of maternal love and unconscious hate. Love and hate, difficult to integrate in any context, can become impossible to manage when the child's infection is a permanent reminder of mother's destructiveness. Mother and child are both inconsolable in the face of certain death.

A factor that may play an important role in disclosure, but that has not been addressed in the literature is the mother's motivation in having the child. A woman may be attempting to repair a sense of integrity of the self or to deal with her shame by having a child with a chance to survive her. The complex conscious and unconscious motivation for the pregnancy undoubtedly influence the mother's handling of disclosure.

Psychological Barriers to Disclosure

Guilt and Shame

The combination of parental responsibility for transmission of a fatal disease and social stigmatization is bound to elicit intense feelings of guilt and shame in the mother of the HIV infected child. In fact, a 1994 study by Wiener et. al. found biological parents of HIV infected childrento score higher on measures of depression, state anxiety, anticipatory grief, and self-blame than did other caretakers, whose measures were also elevated. Another study, by Peterson (1996) found that mothers of hemophiliacs who disclose their child's HIV status had higher rates of depression than those who did not, as a result of perceived stigmatization. An earlier study by Sherman (1993), also found significant relationships between perceived stigma and psychological distress, as disclosure and feelings of estrangement highly correlated with symptoms of anxiety and depression in mothers. The thought of disclosure evokes intense feelings of shame in the mother, who fears exposure of her past, severe criticism and reproach by her child as well as by others. Guilt about infecting the child works together with shame in a complementary fashion: guilt promotes feelings of shame, and shame is a reminder of guilty actions.

Nergaard and Silberschatz (1989) found that patients with high ratings on shame and guilt did not make substantive gains in therapy, possibly related to a finding reported by Adler (1992) that shame and guilt block in-depth self-expression. Levin (1992), in her discussion of group work with parents in the family foster care system, supports the notion that the guilt and shame experienced by parents in relation to their problems lead them to appear unmotivated and distant. It is our experience that mothers who feel guilt, shame, and subsequent depression, tend to be less compliant with medical and psychosocial care. One study, by Tagney, Wagner, Fletcher, & Gramzow (1992) found shame-proneness consistently correlated with suspiciousness, resentment, irritability, a tendency to blame others for negative events, and indirect expressions of hostility.

The importance of parental guilt and shame in preventing disclosure is indirectly supported by our own clinical experience, and by that of the clinicians in the ACTG group, who found that non-family

caretakers were significantly more likely to disclose children's HIV status (Brady, et. al. 1996). As shown by Melvin and Sherr (1993), parents of HIV infected children require much nuturance themselves in order to cope with their own illness and that of their child. The conflicting needs of requiring nurturing and providing nuturance have the potential to overload the parent and motivate defenses against acknowledgment of the illness in themselves or in their children.

Fear of Social Consequences

Many parents fear their children may inappropriately disclose their HIV status to friends, school personnel, and community members, which may result in teasing and ostracism in the community and in school, as well as the loss of support systems for the family and child. Wiener et. al. (1994) notes that fear of rejection, abandonment, and/or discrimination often prevents parents from disclosing HIV status to their family and friends. This fear appears to be well founded, as parents report that, even after disclosure, support often is not forthcoming. Parents also fear that a child faced with such taunting and teasing will experience extreme anxiety (Kirkland & Ginther, 1988). Families experience alienation and anxiety in school settings, as parents of un-infected children frequently respond with fear to HIV infected children in school as demonstrated by the Task Force on Pediatric AIDS (1989), and may threaten to take their children out of school and/or refuse to let their children interact with an HIV infected peer. In fact, all eight children who participated in a support group for HIV positive children reported being teased at one point or another. This is a result of a general lack of knowledge of HIV transmission. When disclosure to schools is conducted in a controlled manner and is accompanied by educational efforts, there is little discrimination against the child and/or family (Clement, Ziegler, & Cruickshank, 1996).

Fear of Causing Harm to the Child

Parents of HIV infected children seem to resist disclosure at least in part to shield themselves, and the children from the full impact of the disease (Lipson, 1993). At times, parents seem to fantasize that disclosure will hasten disease progression, or that treatment and procedures will worsen the child's illness. This seems to be an externalizing mechanism akin to projection, aimed at safeguarding a sense of

protectiveness in the parent. It is our experience that, in an effort to protect the child, parents and caregivers often oppose medical advice or treatment, and resist clinicians' suggestion regarding disclosure. Parents also often fear disclosure will overwhelm and harm the child emotionally. As one grandmother put it while discussing her asymptomatic fourteen year old: "She appears happy enough now. I can't bear the thought of her getting depressed.". In this sense, non-disclosing appears to be an attempt by the parent to protect the child after the fact of infection, as well as a means of avoiding the child's retaliatory rage and rejection.

Fear of Death

Fears of death in the parent and child lead to denial of death, and thus denial of an HIV diagnosis. Or as Lipson (1993) puts it: "discussing my child's infection *equals* discussing my own infection *equals* my guilt, illness, and likely death.". This denial appears to be possible as a result of a split in the ego: denial is co-terminous with acceptance, as, in the vast majority of cases, infected mother and child function according to the reality principle and follow vigorous medical regimens, which are daily proof of their HIV infection. Thus, infected parents' and children's denial processes are in constant tension with memory and reality, as continued treatment and illness progression remind parents and caregivers of their and/or their child's seropositive status. In a few cases, parents evidence phobic responses resulting in complete avoidance of care. For example, a very socially isolated mother of two young infected children, who had not told anyone about the HIV status of her family started attending our clinic, and agreed to participate in a family therapy study. She was required to talk about her infection and that of her children at some length during the baseline interviews of the study, and this seemed to overwhelm her. In spite of numerous attempts of the therapist assigned to the family to make contact with this mother and to establish an alliance, she completely stopped attending the clinic even for medical appointments for many months.

Children's Responses to Disclosure

We interviewed extensively two girls, age eight and nine, in order to obtain their reactions to knowing they have HIV. Both girls were told when very young, and felt they had always known. They felt they should have been told, so they could protect others, for example teachers or peers, and as a means of assuring compliance with medication and hospitalization. Both girls were aware of their possible death.

In the face of parents' secrecy, children will turn to other sources of information. Peter, is a bright and well adjusted fourteen year old boy, who takes only prophylactic medications at this point. His curiosity led him to the library where he explored his diagnosis, as he was aware he had a problem with his immune system. Through research he was able to narrow it down to sickle cell anemia, cancer, or AIDS. He even went so far as to explain to his social worker that he did not think it was sickle cell or cancer, but did not go as far to say it was AIDS. Instead, he asked the social worker to tell him his diagnosis; the social worker had to explain to Peter that his step-mother did not want him to know this. Unfortunately, Peter is now angry at his step mother for withholding this information. As children get older and become knowledgeable and curious about their illness, disclosure becomes inevitable. Furthermore, as HIV-infected children reach puberty, there is danger of sexual contact and possible transmission of HIV.

Disclosure as a Process

Disclosure of a child's HIV status is an ongoing process that just begins when the child is initially informed of seropositivity. The available literature, and our own experience, recommends that disclosure be addressed incrementally. The family may need to develop communication skills before it can address such a terrifying topic. Parents need assistance and time to adjust to the idea of the child's knowing, and repeated opportunities to discuss their fear that disclosure will do more harm than good. It has been recognized that a trusting relationship between health care personnel and the family is a prerequisite for disclosure to children (Brady et. al., 1996; Clement et al., 1996). The family has to be and feel prepared to handle the disclosure. This preparation includes an assessment of the family's needs, modes and

channels of communication, and sources of stress. Since many HIV infected children live in single parent families, with the mother affected by her own illness, it is especially important to provide support and to assist the mother in securing help from her own social network.

Another important variable related to the timing and manner of disclosure is the child's age, cognitive/developmental level, and readiness to learn the diagnosis. Obviously, younger children's intellectual capacities, or the cognitive limitations of children with AIDS dementia preclude sophisticated explanations. They would also be more likely to discuss HIV infection in inappropriate situations. Older children appear to "work their way" to finding out about their illness, as in the case of Peter above. They start asking questions of parents and physicians, and are more capable of demanding answers in a manner that cannot be resisted.

Parents and caretakers choose to disclose to children for a variety of reasons. For example, to avoid further spread of HIV, or to enlist the child's cooperation with treatment. After the child has been told, efforts should continue in the direction of increasing family communication, as disclosure leads to and involves a dialog (Lipson, 1993; Trad et. al., 1994). In our clinic, families are assisted to approach disclosure in the context of their relationships with the pediatricians, through individual and family counseling provided by social workers, and in a support group. As the number of children who know their diagnoses has reached a critical mass, we have started parallel groups for these children and their parents. We are just now beginning to meld these two distinct groups into occasional multi-family groups including the kids and parents together. Here the goal is to increase family communication about HIV.

Clinicians Attitudes and Effects on Practice

The ambivalence and ambiguity related to disclosure seems to be embodied in the split between clinicians and parents or caregivers: most clinicians seem to favor disclosure, while most parents don't. Given the situation, what can be done, pragmatically, to address the issue?

Health care providers function within a complex and sometimes contradictory web of legal, moral, professional, and ethical parameters. In our society, parents have ultimate decision rights regarding their children. Even if the professional thinks disclosure of a child's HIV status may be the socially, emotionally, and morally correct choice, she/he still has to abide by the legal right of the parent or legal guardian to act as the gate keeper of disclosure. The physician can choose to "do battle" with the parent, thus risking the family's leaving care; or may try to pressure the parent in subtle ways; or may try to work with the parent, over time, to alleviate fears and reassure the parent that emotional and social support is available. In the last situation, the physician or other clinician operates on the basis of a conscious (or maybe subconscious) split, allying with the part of the parent which allows for the continued appropriate care for the child and family in the face of seeming denial of illness.

A more dangerous situation occurs when the professional chooses the other side of the split, and views the parent in an adversarial fashion, as a barrier to "doing the right thing". This commonly results in the parent withdrawing more and more from contact with the caregiving staff, not taking proper medical care of herself or the children for fear of being harangued when coming to the clinic. When taken to the extreme, conflict between caregivers and parents can lead to breaches of privacy and confidentiality, or of denial of a child's right to know.

The dilemmas of disclosure are embodied in the following case example:

A sixteen year old girl, possibly infected through sexual abuse, whose mother died of AIDS, is now in the care of a great aunt. The guardian has resisted, over many years, the staff's efforts to disclose the child's HIV positive status, and has threatened to sue the physician and the hospital if he tells. The girl, on multiple prophylactic medications, is otherwise well but comes to the clinic at least monthly. She is beginning to become interested in boys and dating, and has recently increased the specificity of her questions to the physician regarding her illness. The guardian is still warning against disclosure. This is the plight of her physician and clinical staff.

Implications for Research

In the remaining time, we will pose a number of questions warranting empirical research to inform practice with regard to HIV status disclosure to children.

1. Is disclosure beneficial or not? There are no data on the psychological adjustment of children and families who have and have not disclosed. Is there a difference, when all else is controlled for? Does disclosure affect quality of care and/or survival?

2. There is a need to study correlates of disclosure including demographics, support systems, personality variables in parents and children. What is the role of unconscious determinants?

3. Systematic elicitation research with parents and clinicians regarding their attitudes and needs, and of variables facilitating disclosure, would elevate the level of discourse above the anecdotal.

4. Psychologists and psychoanalysts need to become involved in such studies, as they have much to offer, especially in the area of unconscious motivation.

Concluding Comment Regarding Disclosure

Thinking of the seemingly ever growing numbers of children born HIV positive, and of the medical advances extending the lives of these children, it becomes apparent that many children are going to have to live with HIV or AIDS, and that more and more parents will be forced to confront the dilemma of HIV status disclosure. This dilemma is one which requires compassionate thought and inquiry, as well as clinical skill. As psychologists and psychodynamically oriented clinicians, it is our duty to provide the important contribution of psychoanalytic reflection and research on this topic.

References

Adler, S.K. (1992). An object relations view of creative process and group process. Group, 16(1), 47-58.

Brady, et. al. (1996). AIDS Abstracts, XI International Conference onAIDS.

Centers for Disease Control and Prevention. (1995). HIV/AIDS Surveillance Report, December 1995.

Claffin, C.J., & Barbarin, O.A. (1991). Does "telling" less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. Journal of Pediatric Psychology, 16, 169-191.

Clement, L.J., Ziegler, J., & Cruickshank, M. (1996). Taking the tiger by the tail: HIV disclosure in child care and elementary school settings. XI International Conference on AIDS, *We.D. 3605*.

Edmonds (1988). Pssst...it's a secret! A systematic understanding of family secrets. The Social Worker, 56(2), 60-64.

Evans, J. L. (1995). Are children competent to make decisions about their own deaths. Behavioral Sciences and the Law, 13(1), 27-41.

Graham, P. L., Wass, H., Eyeberg, S. M., & Chu, L. (1989). Communicating with dying children and their siblings: a retrospective analysis. Death Studies, 13(5), 465-483.

Greenham D.E., & Lohmann, R.A. (1982). Children facing death: recurring patterns of adaptation. Healt and Social Work, 7(2), 89-94.

Kirkland., M.J., & Ginther, D. (1988). Acquired immune deficiency syndrome in children: medical, legal, and school related issues. School Psychology Review, 17(2), 304-310.

Levin, A.E. (1992). Groupwork with parents in the family fostercare system: a powerful method of engagement. Child Welfare, 21(5),457-473.

Lipson, M. (1993). What do you say to a child with AIDS. Hastings Center Report 23(2), 6-12.

Mellins, C.A., & Ehrhardt, A.A. (1994). Families affected by pediatric acquired immunodeficiency syndrome: sources of stress and coping. Journal of Developmental and Behavioral Pediatrics, 15(3), 54-60.

Melvin, D., & Sherr, L. (1993). The child in the family-responding to AIDS. AIDS Care, 5(1), 35-42.

Nergaard, M.O., & Silberschatz, G. (1989). The effects of shame, guilt, and the negative reactionin brief dynamic psychotherapy. Psychotherapy, 26(3), 330-337.

New York City AIDS Surveillance Report. (1996). Children exposed to HIV in New York city: quarterly surveillance update, March 1996.

Peterson, D. R., Senak, M. S., Etzel, M., & Reed, G. (1996). An assessment of the impact of manditory name reporting on HIV testing and treatment.

Pollock, S.W., & Boland, M.G. (1990). Children and HIV infection. New Jersey Psychologist, 40(3), 17-21.

Pollock, S.W. & Thompson, C.L. (1995). The HIV infected child in therapy. Therapeutic Approaches or Children, Families, and HIV/AIDS Psychosocial and Therapeutic Issues, New York, The Guilford Press.

Schowalter, J.E. (Ed.). (1983). The child and death. New York, Columbia University Press.

Sherman, C. (1993). The psychological impact of acquired immune deficiency syndrome on mothers of hemophiliacs. NYU, Ph.D. Dissertation Abstracts.

Tangney, J.P., Wagner, P., Fletcher, C., & Gramzow, R. (1992). Shamed into anger? the relation of shame and guilt to anger and self-reported aggression. Journal of Personality and Social Pschology, 62(4), 669-675.

Trad, P.V., Kentrose, M., Solomon, G.E., & Greenblat, E.R. (1994). Assessment and psychotherapeutic intervention for an HIV-infected preschool child. Journal of the American Academy of Child and Adolescent Psychiatry, 33(9), 1338-1345.

Tiblier, K.B., Walker, G., & Rolland, J.S. (1989). Therapeutic issues when working with families of persons with AIDS. In: AIDS and Families, New York, The Hayword Press, Inc.

Task Force on Pediatric AIDS. (1989). Pediatric AIDS and human immunodeficience virus infection. American Psychologist, 44(2), 258-264.

Wiener, L., Riekert, K.A., Theut, S., Steinberg, S.M., & Pizzo, P.A. (1995). Parental psychological adaptation and children with HIV: a follow-up study. AIDS Patient Care,9(5), 233-239.

Wiener, L., Theut, S., Steinberg, S.M., Riekert, K.A., & Pizzo, P.A. (1994). The HIV infected child: parental responses and psychosocial implications. American Journal of Orthopsychiatry, 64(3), 485-492.

Zelig, R. (Ed.). (1974). By not telling. Children's Experience with Death, Springfield, Ill., Charles C. Thomas.